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Psychosocial effects on caregivers for children on chronic peritoneal dialysis

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The study was designed to explore the psychosocial effects on caretakers of children in Taiwan on chronic peritoneal dialysis (CPD). This is a case–control study, performed with subjects drawn from eight medical centers. The study group consisted of caretakers of 32 children with renal failure being treated with CPD. For comparison, a control group of caretakers of 64 healthy children as well as the regional Taiwanese studies were used. Two instruments were used to explore the presence of probable depression and quality of life (QOL) of the caretakers: the Taiwanese Depression Questionnaire, and the World Health Organization QOL BRIEF-Taiwan Version. In the study group, only 25% of caregivers had full-time jobs, and 66% of families had an annual income of less than US dollar 15 000. Of the 32 families in the study group, 16% had only a single parent. The prevalence of probable depression was significantly more common in the study group compared with control and referent group (28% vs 5% and 9.44%; $P = 0.001$). QOL scores in four domains were also significantly lower in the study group. In conclusion, even with the advances of peritoneal dialysis techniques, caring for children on CPD in Taiwan has significant adverse psychosocial effects on the primary caregivers. Attention should be paid to the psycho-social status of the caregivers.

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Chronic peritoneal dialysis (CPD) is the preferred renal replacement therapy for children with end-stage renal disease (ESRD). The challenges faced by families in this situation relate to the performance of the health-care system, government funding, acceptance of treatment, demographics, and access to care. Taiwan fortunately has an efficient health-care system, ranking second among 27 major countries in terms of the state of health and quality of medical practice (by 2002 Economist Intelligence Unit report).[1] With an increasingly prosperous economy, advances in CPD technology, and the availability of high quality care, long-term survival of children with ESRD is possible.

However, care for such children still involves considerable psychologic and social stress.[2,3] These children are often dependent on their caregivers for fluid exchange and other dialysis-related home care procedures. The caregivers are essentially on-call 24 h a day and may burn out. Children with ESRD often lag behind their peers because of their illness and may be short and have a strange appearance to other children. In adolescence, they must deal with issues of personal identity, values, and beliefs just as their peers do, but this is particularly stressful in the context of a chronic illness. CPD may further affect family personal relationship and socio-economic status, with potentially serious negative effects on quality of life (QOL). All these factors may intensify the pressure experienced by the caregivers. Brownbridge and Fielding[4] reported poor compliance in pediatric ESRD patients was associated with poor adjustment of their parents. To give supports that meet caregivers' psychosocial and economic needs will consequently benefit the ESRD children.[5]

Although there have been many reports on fatigue for patients with chronic illness and several among caregivers for adults with ESRD,[6–8] this issue has not been explored among those caring for children on CPD. Taiwan has the second highest prevalence of ESRD in the world,[9] making it a logical place to study these questions. This study was designed to explore the psychosocial impact of caring for children with ESRD who are on long-term peritoneal dialysis.

RESULTS

The caregivers' backgrounds, except employment status and household income, were not different significantly between

study group and control group (see Table 1). They were about 42 years old, with female predominant. Five of the children in both study group (15.6%) and control group (7.8%) were in a single parent family. The major differences appeared in study group included: 53% of them were not employed, whereas 25% had full-time and 22% part-time jobs; the annual household income was less than US dollar 15 000 for 66% of the families.

The internal consistency (Cronbach's α) among scores derived from the study and control groups for the two instruments (Table 2) ranged from 0.67 to 0.94, considered good to excellent. Table 3 shows the descriptive data on depression prevalence and scores of World Health Organization (WHO)QOL among study, control and referent groups. With a cutoff score of 19 on the TDQ, nine (of 32, 28%) caretakers in the study group were considered to have depression, of whom five were aware of their depression tendency. This was a significantly higher prevalence in study group than in the control and healthy referent group ($\chi^2 = 13.90$, df = 2, $P = 0.001$). All mean scores in four domains of the WHOQOL were significantly lower in the study group than in control group ($P < 0.001$; df = 1, 94, and F = 32.68, 31.20, 34.88, and 28.40, respectively for physical, psychological, social relationship, and environmental quality).

Regarding the correlation analysis among psychosocial and background factors, the variables of WHOQOL scores in four domains, the presence of depression, the caregivers' perception on health and happiness were found highly correlated with each other ($P < 0.05$). The household income was highly correlated with the employment status as well as the domain scores of psychological, social relationships, and environment in WHOQOL. Dependence for fluid exchange was correlated significantly with the social relationship of life quality. The prevalence of depression in caregivers was not different ($P = 0.34$) between two dialysis modalities applied (i.e., continuous ambulatory peritoneal dialysis and automatic peritoneal dialysis). Patients with dialysis for the longer period of time tended to have lower QOL scores, yet not significantly related. Finally, the duration of dialysis was not different between the caregivers with and without depression.

Multiple regression analysis was used to determine the factors that predicted caregiver's depression and their QOL (see Table 4). The recent health status of the caregivers predicted their depression status (beta = −0.52, the greater wellness perception predicted less occurrence of depression), accounting for 26.8% of the variance. The major factor predictive of a caretaker's perception of his or her physical condition of life quality was the recent health status (accounting for 45.8% of the variance, and beta of 0.68). Depression, happiness, and income were major predictors of the psychological condition of life quality (72.0% of the variance, beta = −0.47, 0.51, and 0.26, respectively). Social relationships of life quality were predicted by happiness and income (40.8% of the variance), and the environmental quality by a felt need for support, income, and the gender of the child (49.4% of the variance). The greater happiness perception and higher income predicted higher scores of social relationship quality (beta = 0.545 and 0.383). The greater felt need for support predicted lower scores of environment quality (beta = −0.331), whereas higher income and female gender of child predicted higher environmental quality scores (beta = 0.439 and 0.31).

Table 1 | The demographic data of the study group (children on CPD) and the control group (healthy children)

	Study group (*n*=32)	Control group (*n*=64)	*P*-value
Children			
Male gender	26 (81%)	52 (81%)	
Age (year)	13.2±3.28	13.2±3.25	
Caregivers			
Male gender	4 (12.5%)	1 (1.6%)	0.07
Age (years)	41.78±4.19	41.63±4.05	0.86
Full employment	8 (25%)	49 (76.6%)	<0.01
Single parent family	5 (15.6%)	5 (7.8%)	0.24
Household income ⩽15 000 USD/year	21 (55.6%)	6 (1.6%)	<0.01
Number of children			
1	2 (6.3%)	8 (12.5%)	0.58
2	17 (53.10%)	37 (57.80%)	
3	13 (40.60%)	18 (28.10%)	
⩾4	0 (0%)	1 (1.6%)	
With disease	12 (37.5%)	16 (25%)	0.51

CPD, chronic peritoneal dialysis; USD, US dollar.
Data were presented as: number (proportion).

Table 2 | Cronbach's *á* among scores derived from caregivers of children on CPD (study group) or healthy children (control group) for the two study instruments (TDQ and WHOQOL)

Instruments	Cronbach's α	
	Study group (*n*=32)	Control group (*n*=64)
TDQ	0.94	0.90
WHOQOL BRIEF-Taiwan Version	0.94	0.90
Physical	0.76	0.64
Psychological	0.81	0.67
Social relationships	0.78	0.77
Environment	0.86	0.80

CPD, chronic peritoneal dialysis; TDQ, Taiwanese Depression Questionnaire; WHOQOL, WHO quality of life BRIEF-Taiwan Version.

DISCUSSION

This study, similar to the reports on ESRD adults[6–8] and the caregivers of children with other chronic illnesses (e.g., asthma, cystic fibrosis, and recurrent otitis media),[10–14] confirms the observation that families with children on CPD are a disadvantaged minority even with the efficient health-care system currently in place in Taiwan. A significant proportion of caregivers in our sample had probable depression, and most of who were not aware of the disorder. The study on children with cystic fibrosis revealed that the

Table 3 | Prevalence of possible depression and perception of QOL: the descriptive data and comparison between the study group (caregivers of children on CPD) and the control group (caregivers of healthy children)/healthy referents

Psychosocial variables	Study group (*n*=32)	Control group (*n*=64)	Health referents (*n*=598 212)
Probable depression: No (%)	9 (28%)	3 (5%)	9.44%*
WHOQOL score (mean ± s.d.)			
Physical	12.84 ± 2.05	15.09 ± 1.69	15.35 ± 1.81
Psychological	11.42 ± 2.65	13.94 ± 1.74	13.70 ± 2.07
Social relationships	12.22 ± 2.37	14.77 ± 1.78	13.99 ± 2.10
Environment	11.89 ± 2.51	14.26 ± 1.78	13.07 ± 2.18

CPD, chronic peritoneal dialysis; QOL, quality of life; WHOQOL, WHO quality of life BRIEF-Taiwan Version.
Probable depression defined as a TDQ score of $\geqslant$19.
Data of health referent were derived from 598 healthy adults for probable depression prevalence rate and 212 for WHOQOL scores.
*Probable depression prevalence rate of health referents was corrected by gender.
*Significantly higher prevalence in study group (χ^2=13.90188, df=2, *P*=0.0010).
Significantly lower mean scores in the study group in the four domains of WHOQOL (*P* < 0.001; F=32.68, 31.20, 34.88, and 28.40, respectively for physical, psychological, social relationship, and environment quality).

Table 4 | Summary of step-wise regression analysis for variables that predicted the presence of depression and the scores of four domains of QOL (physical condition, psychological condition, social relationship, and environmental quality)

Attributes	Standardized coefficients			Model summary		ANOVA	
	Model	Beta	T	*P* (Sig)	R^2	Adj. R^2	F	*P* (Sig)
Depression	(constant)		5.011	<0.001	0.268	0.243		
	Health	−0.517	−3.311	0.002			10.961	0.02
Physical	(constant)		23.149	<0.001	0.458			
	Health	0.677	5.032	<0.001		0.440	25.323	<0.001
Psychological	(constant)		18.790	<0.001	0.720	0.690	24.010	<0.001
	Depression	−0.472	−4.382	<0.001				
	Happiness	0.509	4.792	<0.001				
	Income	0.262	2.541	0.017				
Social	(constant)		18.130	<0.001	0.408	0.367		
	Happiness	0.545	3.801	0.001			9.989	0.001
	Income	0.383	2.670	0.012				
Environmental	(Constant)		15.598	<0.001	0.494	0.440	9.116	<0.001
	Support	−0.331	−2.287	0.030				
	Income	0.439	3.172	0.004				
	Gender	0.311	2.179	0.038				

ANOVA, anlaysis of variance; QOL, quality of life.
Health: recent health status of the caregivers; Physical: physical condition of life quality; Psychological: psychological condition of life quality; Social: social relationships of life quality; Environmental: environmental quality of life; Support: felt the needs for support.
Gender: the gender of the ESRD child.

child's disease severity negatively correlated with the caregivers' QOL; and the relationship existed between the child's and caregiver's health.[13] In this study, almost all the dimensions of the psychosocial impacts on caregivers can be explained by their perception of health as well as lower income. These families had a much lower annual household income than the current mean annual household income in Taiwan (US dollar 15 000 vs 33 583[15]). When compared to the nationwide statistics, the lower income might be explained by the higher unemployment rate (53 vs 3.86%[16]) and higher single parent rate (16 vs 7%[17]). The other risk factors included the perception of depression, as well as the lack of support and happiness.

We found that few of the children under the age of 14 were able to manage their CPD independently. This physical dependence and the long-term demands of caring are coupled with the psychological challenges faced by these children at school and among their peers. Consequently, caregivers are playing many roles for their children, including health-care provider, guidance counselor, and friend, all in addition to the usual demands of parenting a child. It is not surprising, therefore, that these caregivers experience a significantly poorer QOL than do parents of healthy children. These findings were more pronounced in parents of older ESRD children.[2]

There is no question that advances in technology that allows children with ESRD to survive on chronic dialysis are beneficial. However, that tremendous benefit does not come without cost in terms of QOL for both the children and their caregivers. Lew and Piraino[18] reported a low QOL score and depression in adult patients are associated with higher comorbidity, poorer nutritional status, anemia, lower residual renal function, and increased hospitalization rates, whereas increased depressive scores are independently predictive of an elevated peritonitis risk. It is possible that low QOL and depression in caregivers are linked to the

outcome of ESRD children although there has been almost no data up to now.[19] Health care for these children and their families, therefore, should not be limited solely to managing catheters and dialysis solutions. In particular, attention must be paid to the physical, psychological health, and social welfares of the caregivers. Utilization of respite services had significantly reduced the somatic complaints by primary caregivers.[20] Time is ripe to use relevant screening tools for detecting psychosocial problems involving patients and their families, followed by supports to meet their needs, to prevent caregivers from burnout, and improve the quality and length of our patients' lives.

A limitation of the present study is that the data generated from our control group might not represent the whole population in Taiwan. Another limitation is that depression was not confirmed by psychiatric interview. Notwithstanding these limitations, the psychosocial data of the present findings will be used as a basis to offer helps and study the effectiveness of the helps.

Conclusion

Caring for children with ESRD on CPD has substantial adverse psychosocial effects on the caregivers. There should be a high index of suspicion for depression in the caregivers, with appropriate treatment when indicated. In addition, it would be well worth to examining ways to help prevent burnout among these individuals who work very hard in a very high-pressure environment.

MATERIALS AND METHODS

Participants

Caregivers of children on CPD were invited to participate. Their children were managed at eight medical centers in Taiwan. To be eligible for the study, the children cared for had to be younger than 18 years old and have been on CPD for at least 3 months. To compare the status of QOL and the existence of depression, caregivers for healthy children in the control group were selected among volunteered adults bringing their children to the same medical centers for health checks. The children were selected to match for age and gender with the study group, and with other information blind. The enrollment stopped when the expected number of volunteered caregivers (two times the number of study group) achieved. The data were further compared with national data of QOL and the regional prevalence of probable depression.[21,22]

The study group comprised 32 caregivers, either fathers or mothers, of 32 children. The male-to-female (father-to-mother) ratio was 1:7, and their ages ranged from 34 to 50 years old (mean 41.8 ± 4.19). The children included 26 boys (81%) and six girls (19%), with a mean age of 13.2 ± 3.28 (range 6–18) years old. The mean duration of CPD was 40.75 ± 36.42 (3 to 130) months. The modality was continuous ambulatory peritoneal dialysis in 17 cases (53%), and automatic peritoneal dialysis in 15 (47%). Only nine children (28%), the youngest being 14 years old, were able to exchange their dialysate independently. The children of the 64 caregivers in the control group, included 52 (81%) boys and 12 (19%) girls with a mean age of 13.2 ± 3.25 (six to 18) years old. The demographic data with comparison between the two groups are listed in Table 1.

Instruments

To explore the psychosocial impact experienced by the caregivers, we used the following instruments:

(a) Taiwanese Depression Questionnaire (TDQ): The 18-item TDQ developed by Lee *et al.*[23] reportedly has a Cronbach's α coefficient of 0.90 and a sensitivity of 0.89 and a specificity of 0.92 at a cutoff score of 19. A community survey using TDQ in Kaohsiung Taiwan, enrolling 598 adults with female of 52.3% and mean age of 41.4 ± 12.2 years old, yielded a prevalence rate of probable depression of 6.2 and 9.44% when corrected by gender distribution (see health referents in Table 3).[21] The depression prevalence rate in female (10.2%) was 1.5 times more than that in male (6.7%).[21] All the depression data related to caregivers in this study was concluded by TDQ scores, without clinical assessment, and interview.

(b) WHOQOL BREF-Taiwan Version (WHOQOL):[24] This questionnaire is composed of 26 items, with internal consistency (Cronbach's α) and test–retest reliability coefficients of 0.97 and 0.86, respectively. The indices of content validity and concurrence validity are statistically significant ($P < 0.01$). The model contains four domains – physical capacity, psychological, social relationships, and environment – as well as global indicators of QOL and health. Table 3 shows the WHOQOL scores derived from a pilot test delivered to 212 healthy adults (referents) with the mean age of 37.62 ± 12.42 years old.[22]

Data collection

The two instruments were first validated by experts, and then distributed to the caregivers by trained nurses in CPD units. Assistance to complete the questionnaires was provided when necessary. Other demographic information about the children and their caregivers was collected by interview and chart review. All data were kept confidential.

Statistical analysis

Descriptive statistics were used for the caregivers' perception of their QOL and psychological status. The reliability of the two instruments was estimated using Cronbach's α, with face validity provided by 10 experts. A χ^2 test was used to compare the incidence of depression between the control and study groups. analysis of variance was used to compare continuous data generated from the WHOQOL. To select valuable predictors for the presence of depression as well as the scores of QOL measured by the WHOQOL, step-wise regression analysis was performed, with the criteria: probability-of-F-to-enter $\leqslant 0.050$, probability-of-F-to-remove $\geqslant 0.100$. The independent variables included: dialysis duration, dialysis modality, dependence on fluid exchange, patient gender, and caregiver factors of health status, gender, marriage status, household income, disease, religion, employment status, education, and happiness. A P value of < 0.05 was considered to be statistically significant.

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